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Perspectives of Palliative Care Clinical Nurse Specialists' regarding the Management of Delirium in Terminally Ill Patients in the Community --Manuscript Draft--

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Corresponding Author:	Clare Harris The University of Edinburgh Edinburgh Medical School Edinburgh, UNITED KINGDOM
Corresponding Author Secondary Information:	
Corresponding Author's Institution:	The University of Edinburgh Edinburgh Medical School
Corresponding Author's Secondary Institution:	
First Author:	Clare Harris
First Author Secondary Information:	
Order of Authors:	Clare Harris
	Anne Finucane
	Juliet Spiller
Order of Authors Secondary Information:	
Abstract:	<p>Delirium occurs frequently at end of life. Palliative care clinical nurse specialists (CNS) are involved in community palliative care provision. Many patients prefer being cared for at home yet managing delirium in this setting presents unique challenges, potentially resulting in emergency hospital or hospice admission. We examined the experiences and current practice of palliative care CNSs managing delirium in the community. 10 interviews were undertaken. Data was analysed using the framework approach.</p> <p>Challenges to delirium management in the community included limited time with patients, reliance on families and access to medications. Assessment tools were not used routinely; time limited visits and inconsistent retesting were perceived barriers. Management approaches differed depending on CNSs previous delirium education. Strategies to prevent delirium were not used.</p> <p>Conclusions: Community delirium management presents challenges; support surrounding these could be beneficial. Routine assessment tool use and delirium prevention strategies should be included in further education and research.</p>
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Perspectives of Palliative Care Clinical Nurse Specialists' regarding the Management of Delirium in Terminally Ill Patients in the Community

Clare Harris ^a Juliet Spiller ^b Anne Finucane ^b

^a University of Edinburgh Medical School. ^b Marie Curie Hospice Edinburgh.

Abstract

Delirium occurs frequently at end of life. Palliative care clinical nurse specialists (CNS) are involved in community palliative care provision. Many patients prefer being cared for at home yet managing delirium in this setting presents unique challenges, potentially resulting in emergency hospital or hospice admission. We examined the experiences and current practice of palliative care CNSs managing delirium in the community. 10 interviews were undertaken. Data was analysed using the framework approach.

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Conclusions: Community delirium management presents challenges; support surrounding these could be beneficial. Routine assessment tool use and delirium prevention strategies should be included in further education and research.

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Abstract

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Challenges to delirium management in the community included limited time with patients, reliance on families and access to medications. Assessment tools were not used routinely; time limited visits and inconsistent retesting were perceived barriers. Management approaches differed depending on CNSs previous delirium education. Strategies to prevent delirium were not used.

Conclusions: Community delirium management presents challenges; support surrounding these could be beneficial. Routine assessment tool use and delirium prevention strategies should be included in further education and research.

Introduction

Delirium is defined as a disturbance in attention and awareness which has developed over a short period of time, with disturbance in cognition, not better explained by a pre-existing or evolving neurocognitive disorder (DSM-5 2013). It is under-recognised due to the diversity and transient nature of symptoms and potentially misdiagnosing hypoactive delirium as depression or fatigue (Spiller and Keen 2006; Marchington et al. 2012).

Delirium is common across clinical settings (Pendlebury et al. 2015; Marcantonio 2017) but particularly in palliative care, where prevalence is up to 12% at initial community assessment and 88% in the final weeks of life (Watt et al. 2019). Medications, electrolyte imbalances, infection, organ failure and hypoxia may be implicated (Irwin et al. 2013). Delirium indicates poor prognosis in palliative care patients, precipitating increased hospital admissions, morbidity, mortality (Bush et al. 2018), communication loss (Lowe et al. 2016) and patient and family distress (Finucane et al. 2017).

National guidelines inform delirium identification and management (NICE 2010; NHS Scotland 2019; SIGN 2019). In most settings, routine delirium screening is recommended. Tools such as the 4AT can be used for this purpose (<https://www.the4at.com> (MacLulich 2020)). This simple tool is brief, requires no special training, and is used and recommended across clinical settings as a sensitive way of detecting delirium (Bellelli et al. 2014; De et al. 2017; Shenkin et al. 2019; SIGN 2019). Though not yet been validated in palliative care, it is sometimes used in this setting (Baird and Spiller 2017).

Management of delirium encompasses treating potentially reversible causes and using non-pharmacological and pharmacological interventions (Boland et al. 2019). Up to half of delirium cases in terminally ill patients are reversible if underlying causes are identified and treated (Lawlor et al. 2000). Non-pharmacological strategies (orientation, reassurance, noise and light minimization, supporting nutrition, hydration and sleep hygiene, optimizing pre-existing disease management) are recommended to prevent the development of delirium and treat established delirium (Bush et al. 2018; SIGN 2019). Pharmacological management is only recommended where the patient is distressed and

non-pharmacological strategies have failed (SIGN 2019). A recent Cochrane review found little evidence to support pharmacotherapy for delirium symptoms in terminally ill patients (Finucane et al. 2020) and that some drug therapies may worsen symptoms in mild to moderate delirium (Agar et al. 2017).

Many terminally ill people would prefer to be cared for at home (Gomes et al. 2013). Delirium management can be provided in patient's homes (Irwin et al. 2013), yet delirium may still contribute to unplanned admissions if the patient or caregivers become distressed (Boland et al. 2019). Palliative care community clinical nurse specialists (CNSs), provide palliative care to terminally ill people, and their families, in a community setting working collaboratively with other community healthcare professionals (HCPs) who may provide generalist palliative care, such as general practitioners (GPs) and district nurses (DNs).

Few studies have explored delirium management in a community palliative care setting. Given the increases in number of people projected to die in care homes and at home (Bone et al. 2018; Finucane et al. 2019), understanding current practice and unique challenges of the community setting is useful to guide future education, service improvement, and optimize patient care. This study examines Palliative Care CNS experience and current practice managing delirium in terminally ill patients in the community, specifically:

- 1) How is delirium assessed in a community palliative care setting?
- 2) How is delirium managed in the community?
- 3) What challenges are experienced in this setting?
- 4) What additional support could be given to improve delirium assessment and management in this setting?

Methods

Design: Qualitative study with face-to-face semi-structured interviews.

Setting: Specialist community palliative care team working from a hospice base in Lothian, Scotland.

Context: Palliative care community CNSs provide specialist palliative care and support to patients and caregivers in community settings, including symptom control, emotional, psychological, practical and spiritual care. They also provide support, advice and education to GP's and DNs. New patients are comprehensively assessed at an initial visit lasting up to 2 hours. CNSs employed by the community teams involved in this study had been offered in-service delirium educational updates. Several CNSs had additionally been involved in delirium workshops for DNs and care home healthcare providers. These were led by palliative care physicians with case discussions facilitated by CNSs who received training prior to the workshops.

Recruitment: Eligible participants consisted of all CNSs' working across two community teams. The student researcher explained the study and distributed information sheets ahead of interviews. 10 CNSs were recruited take part; 3 eligible CNSs were not recruited due to annual leave. Participants were given participant information sheets and the opportunity to ask questions before signing consent forms.

Data Collection: Face-to-face semi-structured qualitative interviews were conducted by the researcher over a 3-day period in September 2019 in private meeting rooms located at the study site. Interviews lasted up to 30 minutes, were audio-recorded and later transcribed verbatim.

Data analysis: Data analysis was informed by a framework approach, a method of structured thematic data analysis which sorts and views data in a matrix (Gale et al. 2013; Ward et al. 2013). This transparent charting and systematic step-by-step process (Dixon-Woods 2011) increases credibility and dependability (Tobin and Begley 2004). Transcriptions were coded manually by the student researcher

using the computer assisted qualitative data analysis package NVIVO (version 12) to aid on-screen coding and provide a clear trail of analysis (Welsh 2002).

Research governance and ethical considerations: As an evaluation of current practice involving healthcare staff, NHS ethical approval was not required. Marie Curie research governance approved the study on 20/08/2019. Participants provided written consent and were informed they could withdraw at any time. Identifiable information was removed during transcription to ensure anonymization.

Reporting: The reporting guideline COREQ (criteria for reporting qualitative research) was used to aid transparency and structure of reporting (Tong et al. 2007).

Results

Participant characteristics

10 participants were recruited, all were female. Community palliative care experience varied from 1 to 20 years. Seven participants had previously facilitated delirium workshops for DNs and/or care home HCPs and/or attended delirium education sessions (Table 1). Three participants reported no specific delirium training.

Participant	Experience as community palliative care CNS.	Recent delirium training (previous 3 years)
1	>5yrs	Delirium education session. Delirium workshop facilitator
2	>5yrs	Delirium education session. Delirium workshop facilitator
3	≤5yrs	Delirium education session. Delirium workshop facilitator
4	≤5yrs	Nil
5	≤5yrs	Nil
6	≤5yrs	Delirium education session
7	≤5yrs	Nil
8	>5yrs	Delirium education session. Delirium workshop facilitator
9	>5yrs	Delirium education session. Delirium workshop facilitator
10	≤5yrs	Delirium education session. Delirium workshop facilitator
Table 1: summary of participant characteristics		

Themes

6 themes were identified: *challenges of a community setting; detection of delirium; management of delirium; role of informal caregivers; education for CNSs; education for external community healthcare professionals.*

Challenges of a community setting

Participants described challenges of a community setting. Limited patient contact makes identifying symptoms and changes more difficult, especially delirium given the fluctuating nature of symptoms.

“We are only in for a short period of time in the day, we only get a snapshot” P2

Families can provide a patient history but may report symptoms inconsistently and find implementing non-pharmacological strategies difficult.

“The relatives don’t realise it is something to look out for” P10

Night-time agitation was described as particularly challenging in the community. Caregivers are often the only people in the house at this time and may find it difficult to cope.

“A lot of delirium happens overnight, everything is heightened overnight... families are really quite distressed, they are tired, not getting a good sleep and that rubs over into the next day”

P3

Access to and changing medication doses in the community requires prompt prescribing by GPs and is labour intensive for CNSs.

“You can’t increase the doses up the same as you can do in an inpatient unit” P2

Many participants expressed frustration at the lack of delirium awareness among some community HCPs and that they were not alerted to delirium cases soon enough.

“it’s our colleagues not realising that this is what is going on.....not alerting us to a delirium”

P1

Participants reported the difficulty identifying fluctuating symptoms and initiating non-pharmacological approaches in patients living alone; these patients also present safety concerns.

Detection of delirium

Participants mainly assessed for delirium by talking to the patient and observing any symptoms. Information and updates from informal caregivers or DNs were also considered useful.

“(we) know our patients fairly well, so it’s just noticing if there is any changes in their behaviour” P2

All participants reported using the 4AT as a delirium assessment tool if they suspected delirium. A minority reported routine use at initial assessment.

“Picking up cues from the family.... and what you are observing... might prompt something like the 4AT, but it’s not something that I routinely use. P7

Perceived barriers to using the 4AT included limited time at the initial assessment, potential for distressing patients and the lack of clarity regarding frequency and indications for use.

“Visits go on and on forever..... we just have so much to do in that first visit that it’s hard to tailor it all in” P4

Management of delirium

Participants reported looking for reversible causes early in management and treating if appropriate; infection was commonly mentioned. Only one participant mentioned other reversible causes.

“we would look for any reversible causes of delirium, hypercalcaemia, infection, medicines, and make changes as appropriate and try them with antibiotics to see if things help”. P2

Most participants described non-pharmacological strategies for first line management including reassurance, sitting with patient, talking, music, reorientation and sleep hygiene. Three participants did not use non-pharmacological strategies.

“We always look at the non-pharmacological approaches first, re-orientating to time and place for mild delirium, trying to reassure a patient where they are and who they are with.... familiar surroundings.” P3

Pharmacological strategies were predominantly haloperidol based and limited to severe delirium insufficiently controlled by non-pharmacological strategies. A minority described using haloperidol first-line.

“There are occasional situations where nothing works.. and (we have) to sedate them because that is the only safe way of managing them”. P1

When asked directly if they use strategies to prevent delirium, most participants did not explicitly use preventative approaches. One participant suggested trying to prevent triggers for delirium.

“it’s just looking for the triggers that might contribute to delirium and trying to prevent that from happening” P2

Role of informal caregivers

All participants acknowledged informal caregiver’s role in identifying symptoms of delirium, communicating with CNSs and implementing non-pharmacological strategies.

“They know their loved one better than anyone else. They can be quite expert...looking for symptoms and managing symptoms and communicating that things are different” P5

Participants described educating caregivers to enable them to assist with detection and management.

“I think just the families knowing who they can contact.... talking them through the non-pharmacological stuff like reassurance, familiar things around them, calm environment.” P2

Participants perceived that caregivers felt more in control when they were educated and benefited from having something to do.

“Hopefully you are also managing someone’s anxiety and they know what to expect and are able to kind of, feel more in control to report that and have it managed” P6

Participants did not routinely discuss delirium on first assessment. Preventing unnecessary distress was the main reason for not preparing caregivers earlier.

“I think sometimes it can be difficult to put something into somebody’s mind and say this may happen...potentially it gives them something to worry about.” P8

Earlier education of caregivers was suggested by participants. One suggestion was providing written information to caregivers ahead of time.

“if we spoke to the families about maybe pre-empting delirium and say look, this may happen and look for these signs.” P8

Education of CNSs

Management of delirium differed between participants who had facilitated delirium workshops for external community HCPs and those who had not. Workshop facilitators focused on non-pharmacological management, engaged caregivers in identification and management, and used pharmacological interventions only when necessary to control symptoms.

“guiding the family as to what they can do, you know did they like music, having that playing in the background, having things that are familiar to them round about” P2

Conversely, those without delirium education favoured early pharmacological intervention, rarely used non-pharmacological interventions or involved caregivers, and seemed less confident in their practice.

“I have never thought about families checking (for symptoms of delirium) before.” P4

Several participants expressed the benefit of facilitating delirium workshops in order to consolidate and reinforce their knowledge.

“facilitating delirium workshops offered to the district nurses, that is always a refresher to us as well, listening to the presentation.” P2

Education for external community healthcare professionals

Improving education for community HCPs was commonly suggested. Participants involved in delirium workshops expressed the difference they noticed in HCPs awareness of delirium after attending the workshops.

“Upskilling our external colleagues, which we are doing, (has) been really helpful actually and they have found it really beneficial.” P3

Discussion

This study demonstrated the unique features of assessing and managing delirium in a community setting. Limited time with patients, relying on caregivers and access to medications make managing delirium difficult in the community. Awareness of these challenges raises suggestion of where improvements could be made, for example earlier caregiver education to help identify delirium and implement non-pharmacological management (Finucane et al. 2017). Good collaboration with DNs could alleviate some of the time constraints and information sharing with general practitioners could optimize access to anticipatory medication (Brajtman et al. 2006; Tapsfield et al. 2016).

Participants reported using a delirium screening tool such as the 4AT only when delirium was suspected, owing to time constraints, concerns regarding distressing patients, and the need for repeated assessments to detect delirium. This potentially misses early or hypoactive delirium. Inconsistent delirium screening is prevalent in palliative care (Boland et al. 2019) despite recommendations to screen all patients and repeat screening regularly (Bush et al. 2018). Time spent completing the 4AT may prevent distress long-term with early detection and management (Partridge et al. 2013; Bellelli et al. 2014). Some participants were unclear whether multiple 4AT assessments were needed to detect delirium, despite the 4AT being designed for single assessment, not monitoring (MacLulich 2020). Ongoing education and training regarding the 4AT in community contexts should be considered given its potential benefits as a brief assessment tool (Bellelli et al. 2014).

Participants rarely discussed reversible causes of delirium other than infection, suggesting they may occasionally go undetected and untreated (Lawlor et al. 2000). Increased awareness of these could prevent negative outcomes of uncontrolled delirium. In this study, a minority of participants did not employ non-pharmacological interventions. Given guideline recommendations stating their potential for benefit and absence of harm (SIGN 2019), all CNSs should implement these first-line. Participants generally used pharmacological strategies in accordance with guidelines, only in moderate/severe delirium where non-pharmacological approaches had proved ineffective (SIGN 2019). Based on

inefficacy and harms of pharmacotherapy in mild/moderate delirium (Agar et al. 2017; Finucane et al. 2020), antipsychotics should be avoided in these patients.

None of the participants explicitly used strategies to prevent delirium development. Evidence from hospitalized populations suggests non-pharmacological interventions potentially reduce delirium incidence (Hsieh et al. 2015; Oh et al. 2017) and guidelines recommend their use (SIGN 2019); prevention strategies should be included in future delirium training.

Participants acknowledged the importance of informal caregivers in supporting care in the community where nursing presence is less. Caregiver's intimate knowledge of the patient can help identify early delirium (Kerr et al. 2013; Finucane et al. 2017) and they are well placed to try non-pharmacological prevention and management strategies (Martinez et al. 2012). Literature suggests being able to help the patient also benefits caregivers (Irwin et al. 2013). Participants generally offered advice to caregivers once delirium or risk factors were identified. Evidence suggests that caregivers prefer being prepared earlier of the possibility of delirium developing, as preparation could reduce distress and increase their confidence aiding delirium identification and management (Gagnon et al. 2002; Otani et al. 2013).

Participants who had facilitated delirium workshops felt that receiving education prior to the workshop and then reinforcing it by facilitating discussions with others was beneficial to their learning. They reported clinical practice more consistent with current guidelines. Learning with the anticipation of teaching others has been shown to result in a greater depth of understanding than learning alone (Fiorella and Mayer 2013). Participants also identified the increased knowledge of delirium among HCPs who participated in delirium workshops. Given the potential educational benefit for facilitators and attendees (O'Brien et al. 2001), more people could be encouraged to get involved in workshops or other delirium education initiatives. Such approaches, bringing together palliative care specialists with professionals providing essential non-specialist palliative care in the community are often recommended and help ensure that more people dying in a community setting receive good palliative care when needed (Murray et al. 2017; Finucane et al. 2019).

As delirium is commonly experienced by people approaching the end of life, district nurses should be aware of delirium and liaise closely with caregivers to identify symptoms; using a delirium assessment tool use could be beneficial. Understanding national delirium guidelines and seeking advice from specialists when required will help ensure good management of delirium in the community.

Strengths and limitations

As far as we are aware, this is the first qualitative study examining the perspectives of CNS regarding assessment and management of delirium in a community setting. However, as an evaluation of one specific palliative care setting, results may not be generalizable to other contexts. Most participants in this study had previously received some delirium training. In settings without such training, insights into delirium and its management may differ.

Further directions

Given the projected increase in need for community palliative care provision (Etkind et al. 2017), research is needed focusing on community management and prevention of delirium, in order to guide clinical practice and reduce negative sequelae. Further studies to design, evaluate and implement delirium education interventions for caregivers, DNs, GPs, and palliative care CNSs are required.

Conclusions

Challenges in identifying and managing delirium in palliative care in the community include access to family carer support; limited time with patients; night-time symptoms; access to and changing medications. Training and collaboration with families and community colleagues are possible strategies to address these challenges. Formal delirium assessment tools were only used where delirium was already suspected; more consistent use of these tools may improve early detection. CNSs acknowledged informal caregivers' role in identifying and management of delirium in the community; early, consistent caregiver education could be implemented.

Keywords

Palliative care. Community care. Hospice. Delirium. Education. 4AT

Key points

- Many palliative care patients would prefer to be cared for at home, yet delirium can contribute to unplanned admissions if symptoms are not adequately managed and the patient or caregiver are distressed.
- Challenges of managing delirium in palliative care in the community include limited patient contact, reliance on family, night time symptoms, patients living alone, access to and changing medication and lack of awareness of delirium among some community healthcare professionals.
- Delirium assessment tools are not routinely used by CNSs, with limited time, potential for distressing patients, and inconsistent retesting described as perceived barriers.
- The majority of participants described using non-pharmacological strategies (reassurance, reorientation, noise and light minimization, sleep hygiene, hydration) for first line management of delirium though did not employ these strategies preventatively.
- CNSs felt that informal caregivers had a role in identifying and managing delirium in the community and they as CNSs had a role in providing education to the caregivers.

- CNSs who had previously facilitated delirium education workshops for external community healthcare professionals felt the workshops helped to consolidate their own knowledge and described assessment and management strategies more in line with current guidelines than those CNSs who had not facilitated workshops.

Reflective questions

- How do you currently assess and manage delirium in your setting?
- What education and training have you received regarding managing delirium in the community?
- How could you incorporate delirium assessment tools such as the 4AT into your practice?
- How could you incorporate delirium prevention strategies in your practice?

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Participant	Experience as community palliative care CNS.	Recent delirium training (previous 3 years)
1	>5yrs	Delirium education session. Delirium workshop facilitator
2	>5yrs	Delirium education session. Delirium workshop facilitator
3	≤5yrs	Delirium education session. Delirium workshop facilitator
4	≤5yrs	Nil
5	≤5yrs	Nil
6	≤5yrs	Delirium education session
7	≤5yrs	Nil
8	>5yrs	Delirium education session. Delirium workshop facilitator
9	>5yrs	Delirium education session. Delirium workshop facilitator
10	≤5yrs	Delirium education session. Delirium workshop facilitator
Table 1: summary of participant characteristics		